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HUMAN IMMUNODEFICIENCY VIRUS ANTIBODY TESTING AND THE RIGHT OF PRIVACY

By

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I. INTRODUCTION

States. The disease's causative agent, the Human Immunodeficiency Virus, HIV, appears to have infected an additional number of asymptomatic people. Both the disease and the infection are shrouded with misinformation and misunderstanding. The public reaction is that of fear and discrimination against both the infected and the ill. Blood tests exist for the detection of antibodies to the virus. There is tremendous pressure from the public to use the virus antibody tests, originally invented to screen the nation's blood supply, to screen the infected from the uninfected. The danger is that the results of the tests will be misused.

This paper examines HIV antibody testing, its meaning, and the legal protections available to prevent unwarranted disclosure. Legal protections include federal statutes, the United States Constitution as interpreted by the U.S. Supreme Court and the appellate courts, state constitutional law, the state physician-patient privilege, medical records statutes and finally specific state laws on HIV antibody testing. It will be shown that many of the laws are very narrow in scope and that the right of privacy is subject to conflicting public health and public policy interests. No single law offers the protection desired by a person infected with the HIV; rather, a combination of laws or doctrines must be used.

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TABLE OF CONTENTS

I. INTRODUCTION	1
II. AIDS AND HUMAN IMMUNODEFICIENCY VIRUS ANTIBODY TESTING	2
III. FEDERAL LAW	9
Particular Statutes	9
U.S. Constitution	1
First Amendment	12
Fourth and Fifth Amendments	14
Fourteenth Amendment and Equal Protection	10
Substantive Due Process and the Right of Privacy	2:
The Courts of Appeal	27
Public Health	31
Public Policy	3
IV. STATE LAW PROTECTION OF PRIVACY	3
State Constitutional Right of Privacy	40
Physician-Patient Privilege	4:
Medical Records	4
Specific HIV Antibody Testing Legislation	4(
v. <u>conclusion</u>	49
<u>FOOTNOTES</u>	5
RESOURCES CONSULTED	50

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II. AIDS AND HUMAN IMMUNODEFICIENCY VIRUS ANTIBODY TESTING

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The illness called Acquired Immune Deficiency Syndrome, abbreviated AIDS, is the end stage of the infection by the Human Immunodeficiency Virus, HIV (formerly known as Human T-Lymphotropic Virus Type III, HTLV III and Lymphadenopathy Associated Virus, LAV or a combination of those terms: HTLV/LAV). The syndrome is a set of symptoms that occur together and indicate a poorly functioning immune system. The virus invades certain white blood cells, the T-Lymphocytes, particularly the T-helper cells, which are an integral part of the human immune system. When these cells are damaged, the body cannot fight infection and becomes highly susceptible to viruses, protozoa, bacteria, parasites and fungi. 1

when the HIV attacks the white blood cells, the body produces antibodies. The infected person is asymptomatic but is considered to be capable of infecting others. A person may be without symptoms of disease for years. Another stage of HIV infection is the AIDS-Related Complex or ARC. The person may have such health complaints as loss of appetite, swollen lymph nodes or tiredness. Because these symptoms may be indicative of other diseases, persons exhibiting them require further medical testing.

Some infected individuals may proceed from ARC to AIDS, others may never have ARC, but instead develop AIDS. The Center for Disease Control (C.D.C.) definition of AIDS is HIV exposure

associated with an immune deficiency in a person not otherwise at risk (for example, not taking drugs to suppress the immune system as an organ transplant donee) and the presence of an opportunistic infection, Kaposi's sarcoma, dementia, wasting illness, or non-Hodgkin's lymphoma. 3 Typical opportunistic infections include Pneumocystis carinii pneumonia (caused by a protozoan), cryptococcal meningitis (fungus), central nervous system toxoplasmosis (protozoan), cytomegalorius (a herpes family virus causes severe diarrhea), candidiasis or thrush (caused by a fungus), tuberculosis (caused by bacteria) and cryptosporidosis, also causing severe diarrhea (protozoan disease). Besides invading the white blood cells, the HIV may invade the brain and nerve cells causing neurological impairments such as dementia. The infected person becomes weaker and weaker and eventually succumbs to one of the infections or to cancer such as Kaposi's sarcoma. Technically it could be said that the person does not die of AIDS or of HIV infection, but with AIDS as the result of another disease that overwhelms the body.

AIDS is believed to have surfaced in Africa in the 1960's.

It occurred in the United States in scattered cases of Pneumocystis carinii pneumonia in the 1970's but was not recognized as a separate disease. Not until 1981 and 1982, when physicians reported an unusual number of incidences of Pneumocystis carinii pneumonia, Kaposi's sarcoma and generalized lymphadenopathy (swollen lymph nodes) in otherwise healthy young men to the CDC, was the disease recognized. The majority of the early cases involved young homosexual and bisexual

men. The disease was suspected of being viral and transmitted sexually.

Then it appeared in intravenous (IV) drug users and finally hemophiliacs thereby establishing a blood connection to transmission.

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In 1984, researchers in France and the United States isolated the virus, HIV, believed to cause AIDS. Although the HIV has been isolated in semen, blood, and other body fluids, transmission of the infection is primarily through sexual contact, the sharing of needles and, now less frequently, transfusions of infected blood or blood components. 4 Casual contact does not spread the virus. There is no evidence of transmission of HIV to family members who live with an individual who has AIDS. 5

A breakdown of the AIDS cases whows the sufferers to be primarily sexually active homosexual or bisexual men (73 percent), followed by present or past intravenous drug users (17 percent), recipients of blood transfusions (2 percent), hemophiliacs (1 percent) and infants born to infected mothers (1 percent). To date approximately 36,000 cases of AIDS have been reported to the C.D.C. The mortality rate (ratio of dead to total cases) is about fifty percent (half the reported persons have died) and the fatality rate (final outcome of the disease) is 100 percent. Estimates are that the number of cases doubles every eleven months. For every reported AIDS case, there are an estimated fifty to one hundred infected, asymptomatic carriers. Although scientists do not know how many of these carriers will develop AIDS, the best guesses are that five to twenty percent will develop AIDS and an additional twenty-five percent will develop ARC.

vaccine against HIV and there is no cure for AIDS.

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The first license to manufacture a test kit to test blood for the HIV (then HTLV III) antibodies was issued in 1985. Because the presence of antibodies indicates exposure to the antigen, in this case HIV, the nation's blood services began to use the new test to screen the blood supply. Use of the HIV antibody test expanded from the blood services and is now available to individuals through state health departments, sexually transmitted disease clinics, doctors' offices, military testing facilities and so-called "alternative" test sites. Two types of tests are available. ELISA, the Enzyme-Linked Immunosorbent Assay, is of more widespread use. It is sensitive enough to detect the antibodies, but its lower specificity gives it a high rate of false positives. If the first ELISA test is positive, a confirmative ELISA test is run a second time. If it is still positive, then a second type of test, the Western blot is done. Western blot is more specific than ELISA for antibodies but it is more expensive and complicated to run. Unfortunately, the error rates or the reliability of the ELISA test varies from laboratory to laboratory. The interpretation of the Western blot also can wary. That test is designed so that the HIV antibodies show a pattern of stripes or bands. Some laboratories considered the presence of one band as a positive result. The American Red Cross requires three bands. Obviously there is tremendous concern by health authorities about false positives because increased testing affects quality control by overburdening laboratories or encouraging the rise of poorly supervised

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laboratories. ¹⁰ Off equal concern is the false negative result.

Once an individual is infected with HIV, it may take the body up to twelve weeks to develop antibodies. A test taken during this period could result in a negative finding that was false. The individual would then incorrectly conclude that he or she was not infected. ¹¹ This person could unwittingly infect others.

The meaning of a positive test result is quite limited. The seropositive individual has been exposed to HIV and probably is a carrier of the virus. More important is what the test does not mean. It is not diagnostic: it does not test for AIDS. It cannot predict that the individual will develop ARC or AIDS. It does not count the number of T-lymphocytes or evaluate the body's immune response; other tests are available for these purposes. Yet in the public's mind, HIV seropositivity is the same as AIDS. The fear of AIDS because it is a new, fatal disease, and the stigma attached to it because the majority of cases have occurred in homosexual men and I.V. drug users, have given grave consequences to HIV antibody testing.

Public fears have generated a political response to HIV antibody testing. The Reagan administration has proposed "routine" testing for marriage license applicants, prisoners, and people tested at venereal disease clinics or drug treatment centers. The Department of Defense requires mandatory testing of military recruits and of military members. Recently, immigrants to the United States were made subject to mandatory testing. Testing raises the question of whether it should be voluntary or mandatory; who should be tested;

how often should the test be performed; whether the testing should be anonymous; whether the names of the seropositive should be reported to public health officials; and whether the names of sexual or drug contacts should be solicited and then traced. Mindful of these issues and the medical aspects of AIDS, the Surgeon General of the United States has taken the position that compulsory testing is unnecessary. 12 The American Medical Association rejected the Reagan administration's call for expanded routing testing and urged instead widespread voluntary testing and counselling. 13 Columnists have suggested that politicians are using the AIDS epidemic to discriminate against homosexuals or that the proposed testing simply is illogical: for example, because the disease is sexually transmitted it is very underinclusive to test only marriage applicants instead of all sexually active people. 14

As election year 1988 approaches, few politicians will refrain from taking a position on testing and its impact on privacy.

A positive HIV antibody test result can be personally devastating; the individual must face the fact of life long infection and the potential of developing AIDS. If the results are not kept in confidence the individual may be subject to the same discrimination as the person who has AIDS: loss of employment, insurability, housing and friends.

In addition, public health officials fear that breaches of confidentiality will cause the infected, or those who suspect they are infected to avoid testing and health care, thereby frustrating epidemiologic

studies and endangering others. They recommended that state legislatures pass laws ensuring confidentiality, punishing unauthorized disclosure and prohibiting discrimination against not only persons with AIDS but persons with positive HIV antibody test results. 16

Next to the inconclusive meaning of a positive HIV antibody

test result, the most troubling aspect of the test is confidentiality.

The majority of individuals would not want the positive antibody

status disclosed to the public or even to an employer or insurance

company. Controlling this data is difficult because the testing is

not centralized. Blood banks test as do private clinics and public

health service (state and federal) clinics. Hospitals perform tests.

Antibody status may be found in health records, on blood donor

deferral lists, on laboratory reports or in experimental data.

This information, status and possibly names (some testing is anonymous)

is held privately, or by state or federal agencies. State laws can

change, so conceivably a state that at one date required no reporting,

even of AIDS could later require reporting of the names of persons

who are positive for HIV antibodies.

Just as the HIV antibody testing is diverse, so are the laws protecting privacy. Both federal and state law may provide some protection, but as will be discussed, there are severe limits to the amount of coverage and protection. Also useful are the laws concerning the physician-patient testimonial privilege and laws governing medical records. The long standing deference to public health laws by the

courts make most laws inadequate to protect confidentiality in HIV testing. When breaches of confidentiality occur, there are few remedies. Damages cannot restore confidentiality.

III. FEDERAL LAW

Particular Statutes

When HIV antibody status is contained in medical records held by the federal government, some protection against disclosure is afforded by the Freedom of Information Act (FOIA) 17 and by the Privacy Act of 1974. ¹⁸ The FOIA generally allows public access to government held information. Subsection (b)(6) of the Act exempts personnel and medical records along with similar files "the disclosure of which would constitute a clearly unwarranted invasion of privacy." This should prevent parties outside the government from seeking HIV antibody status by requesting an individual's medical or personnel record. The Privacy Act prohibits disclosure of any record in a system of records without the consent of the person to whom the record pertains. This Act contains two exceptions. One is the "routine use" and the other is "compelling circumstances." 19 Basically routing use allows disclosure "for a purpose which is compatible with the purpose for which the information was collected. 20 The individual's consent is not required for this type of disclosure. Subsection (8) allows disclosure "to a person pursuant to a showing of compelling circumstances affecting the

health and safety of an individual ... ". Consent prior to disclosure is not required but notification of the disclosure to the individual's last known address is required. It is not difficult to imagine a third party presenting "compelling circumstances" in order to obtain an individual's HIV antibody status. If it can be said that in spite of the exceptions the Privacy Act does protect confidentiality, it does so only if the information is retrievable by the individual's name or identification number. This overlooks the capability of computer searches that do not require names or identifiers, yet can locate very sensitive information. 21

Other federal laws may provide some protection against unauthorized disclosures of medical information. Under the regulations for the Protection of Human Research Subjects, 22 entities doing research with human subjects that is funded by the Department of Health and Human Services (HHS) are required to have an institutional review board (IRB) whose function is to protect the rights and welfare of the subjects. In order for the entity to obtain HHS approval, it must follow the regulations which include a requirement for the IRB to make certain, where appropriate, that there is adequate protection of the subjects' privacy and the confidentiality of the data. 23

Practice has shown that HHS is more concerned with the physical safety of subjects than with their privacy. According to one author, IRB's rarely have reviewed research protocols to prevent unwarranted disclosure of confidential information. 24

The Drug Abuse and Treatment Act of 1972 protects medical records of persons undergoing treatment from disclosure. 25 The Secretary of Health and Human Services may authorize researchers to protect the privacy of their subjects in studies or mental health and alcohol and drugs. ²⁶ The researchers may withhold the names and identifying characteristics of the subjects. Information gathered by researchers funded by HHS for statistical and epidemological studies may be used only for the purpose for which it was gathered, i.e. the study. Disclosure for other purposes requires the subjects' consent. 27 These federal laws concerning research and drugs could be used to protect the HIV antibody status from disclosure since a large number of I.V. drug users have the antibodies. The protection is very narrow because the basic requirement is that the individual must be involved in research or treatment to which the laws apply. Therefore, the protection is more theoretical than practical.

It seems unlikely that the federal laws will be of any use in assuring that confidential or private information in medical records, particularly HIV antibody status, is protected from disclosure.

There are either broad exceptions to nondisclosure or the number of protected individuals will be so small that there will be little impact.

U.S. Constitution

The right of privacy, or the right to be let alone as it has been called, 28 is not one right but rather several related rights

supported by the Amendments to the U.S. Constitution, particularly the First, Fourth, Fifth and Fourteenth Amendments. The right of privacy is situational or dependent on circumstances. It can be applied to HIV antibody testing, but because the right is not absolute, it does not provide strong protection.

First Amendment

The First Amendment protects freedom of speech, press, assembly and petition. It has been applied to guarantee freedom of association and in this context it protects one aspect of group members' privacy. The ability of an association to function may depend on its success in concealing the names of its members. A disclosure of the names would subject members to hostility and would result in discouraging their further association. State actions which infringe on this right deny a liberty right guaranteed by the Due Process Clause of the Fourteenth Amendment. 29 In N.A.A.C.P. v. Alabama, 30 the Supreme Court denied effect to a state court order requiring product of the N.A.A.C.P. membership lists. The Court found that the state had no compelling interest that would justify the deterrent effect on freedom of association that disclosure would create. 31 A slightly different fact setting is found in Shelton v. Tucker 32 which involved an Arkansas statute requiring teachers to divulge their membership in all organizations to which they had or were paying dues or making contributions for the past five years as a condition of employment. Unlike N.A.A.C.P. v. Alabama, the Court found that the state had an interest in determining the fitness and competence of its teachers. However,

the required disclosure was so broad that is covered information relevant to the states' interest and information irrelevant to it.

It impared the teachers' right of freedom of association. The Court concluded that the statute did not provide that the information given by the teachers be kept confidential; the school boards were free to deal with the information as suited them; and that the record showed there was a real danger of disclosure to third parties.

Although both N.A.A.C.P. v. Alabama and Shelton v. Tucker appear to be old, settled law, they present an approach applicable to one aspect of HIV antibody testing. Organizations exist that promote the civil rights of persons with AIDS, and those who are HIV antibody positive. The organization may be specific in its interests, such as the National Association of Persons With AIDS, or it may consider the protection of the rights of persons with AIDS to be one of many issues, as in the case of a homosexual rights group. It is conceivable that a state agency through a court order or through legislation might attempt to obtain membership lists of organizations for the purpose of learning antibody status. Equally plausible would be the attempt to force an individual to divulge his or her associations in the hope that a connection to either a homosexual rights or persons with AIDS group would be discovered. Of particular importance is the balancing of interests that the Supreme Court appears to have done in both N.A.A.C.P. v. Alabama and in Shelton v. Tucker. The state agency desiring membership information should be held to the standard of a compelling interest because of the liberty interest in freedom

of association. Because disclosure of membership is associated with a positive antibody status, it would subject the members to public hostility and have a chilling effect on further association with the group.

It is important to note that the Supreme Court has limited its discussions on freedom of association to those groups whose activities are covered by the First Amendment. 34 This would eliminate associations that are medical or social from protection. A group whose members are predominately HIV antibody positive should consider including some type of political activity on its agenda to ensure some type of constitutionally protected freedom of association for its members.

Fourth and Fifth Amendments

Both the Fourth and Fifth Amendments provide privacy protection for the individual who desires to keep particular types of information from the government. Traditionally, the Fourth Amendment protected a seclusion interest rather than personal privacy. As methods of searches and seizures became more sophisticated and ceased to require physical intrusion, the protection of the Fourth Amendment was expanded by the Supreme Court. Seatz v. United States, a case involving electronic eavesdropping on a telephone booth, moved the Fourth Amendment's protection toward confidentiality of information. The Court declared that "the Fourth Amendment protects people, not places" and reasoned that Katz was entitled to assume that his telephone call would not be broadcast.

protection to the telephone call and to the information (in this case gambling information) conveyed in that call.

The Fourth Amendment's protection generally is limited to criminal investigation. However, it has been used in a noncriminal setting. Former President Nixon asserted, inter alia, that his right to privacy had been violated in Nixon v. Administrator of General Services.

The Supreme Court conceded that Nixon had a reasonable expectation of privacy in his purely personal papers but ultimately ruled against him on other issues. This particular case will be discussed later as it relates to disclosure of information, but it is a rare instance of the Supreme Court recognizing a Fourth Amendment right of privacy in a noncriminal case.

It is doubtful that the Fourth Amendment's coverage will be expanded to include a generalized right of privacy. Therefore its application to HIV antibody testing is limited. An individual would need to possess information of his or her antibody status in such a manner that a reasonable expectation of privacy would exist. For example, if a home testing kit for the presence of HIV were to be developed (one might speculate on the possibility of testing for something other than antibodies that would indicate exposure to HIV; advances in technology made home testing for pregnancy possible and there is no reason to assume that as more is known about the HIV, simpler screening tests cannot be developed), the results of that test might fall under the expectation of privacy. On a more practical level, the private telephone conversation that reveals HIV antibody status should receive the same protection as

Katz telephone call. The difficulty is that the conversation must be heard by an agent of the government. The Fourth Amendment does not protect information that is given to private individuals, even if they are informants for the government. 40

If anything, the Fifth Amendment's protection of privacy is more limited than that of the Fourth Amendment. It allows the individual to refuse to divulge to the government incriminating information about himself or herself. Being HIV antibody positive is not a crime, just as being a drug addict is not a crime. Given a hypothetical law which made unprotected sexual intercourse by a HIV carrier a crime, that person would be most reluctant to disclose his or her antibody status to criminal investigators if he or she were a carrier.

The conclusion to be drawn from this discussion of the Fourth and Fifth Amendments as they relate to the right of privacy and HIV antibody testing is that they provide little protection. They are of some use in the unusual circumstance that involves a criminal investigation. Fourth Amendment protection could be asserted as an alternative argument to prevent disclosure to the government; however, a litigant would be unwise to place must reliance on it.

Fourteenth Amendment and Equal Protection

The Fourteenth Amendment provides two avenues of attack on laws that impinge on the privacy of those who are HIV antibody positive.

The first, although not strictly involving privacy, is the guarantee of equal protection. The second is substantive due process. In using the former, one argues that the particular law discrimination against

a group. The latter argument contends that the right of privacy has been denied.

Equal protection requires the state to have a defensible reason for classifying persons and treating them differently from those who are not members of the class. Equal protection allows several levels of judicial review. At the most tolerant level, the mere rationality test, the state's means must be rationally related to the desired end. 42 Courts use minimal scrutiny of the challenged law. Judicial intervention is rare and deference to the state's purpose is high. Under minimal scrutiny, it is nearly impossible for a plaintiff to persuade a court to declare a state's law unconstitutional because, with rare exception, there is some rational connection between the law and the state's intent or goal.

At the other end of the spectrum is the strict scrutiny standard. It is used where there is a suspect classification that impairs a fundamental right (such as voting or interstate travel). 43 Under the strict scrutiny standard, the state is required to show that the classification is necessary to satisfy a compelling state interest. At this level of scrutiny, it is very difficult for a state to sustain that burden.

Equal protection law is not an all or nothing proposition. Under minimal scrutiny the state's law was upheld. Under strict scrutiny, the state lost. A third test, heightened scrutiny was developed. It was used for sensitive classifications like alienage 44 and illegitimacy, 45 or where classifications impair important but not fundamental interests

such as education. 46 Under heightened scrutiny, the state must show a direct, substantial interest between the classification and the achievement of the state objective. 47 The determination of what constitutes a sensitive classification, uses the same factors as the suspect classification. 48 They are few in number: a history of discrimination, political powerlessness, stigmatization and immutability. 49 No one characteristic is determinative of a suspect classification, but if the combination of the factors shows the group to be a "discrete and insular" manority, their special treatment by the courts is allowed. 50

Equal protection arguments can be applied to laws affecting those persons with positive HIV antibody status by looking at the membership of the class and by reviewing the importance of the state's interests. One approach to the status of the group has been an analysis of the largest group of seropositive individuals -- homosexuals. Eloquent argument has been made that homosexuality deserves the status of suspect classification. The is beyond cavil that homosexuals have a long history (centuries old) of discrimination and stigmatization. Yet the Supreme Court has not conferred the status of suspect or sensitive classification on homosexuals and has upheld state laws prohibiting homosexual sodomy, most notably in Bowers v. Hardwick. The seems unlikely that courts will confer a special status on homosexuality; therefore an equal protection attack on this basis will not be successful.

Another look at the membership of the positive HIV antibody group shows it to be made of members of groups that enjoy judicially favored status. A great portion are Black people and Hispanic people. Race

and national origin are suspect classifications. Alienage is at least a sensitive classification. There is a potential argument that laws which discriminate against persons who are HIV antibody positive are also discriminatory against Blacks and Hispanics. Therefore the group is deserving of sensitive classification status at a minimum. Additionally, the stigmatization of HIV carriers, the immutability or inability of them to control their "membership" in the groups (at least up until the time that scientists discovered the cause of AIDS and how it is transmitted), defines them as a discrete and insular minority. Although it can be argued that any lifelong infection such as herpes simplex II (also known as genital herpes) or hepatitis B carriers might be called a sensitive classification, the HIV carriers clearly are distinguishable because of the public fear and loathing and mortality associated with AIDS.

Assuming, arguendo, that positive HIV antibody status is a sensitive classification, the next step is an analysis of the state's interest in legislation that discriminates against the class. Colorado statute requires the reporting by name and address not only of those persons with AIDS, but also those infected with HIV. 53 A helpful analysis of the state's interest in the reporting requirement is in the Cardozo Law Review. 54 The four stated purposes of the law ---

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- (1) to alert health agencies to the presence of persons likely to be infected with a highly dangerous virus;
- (2) to allow health agencies to ensure that the infected were counselled as to the meaning of the antibody

- test and how to prevent transmission of the virus;
- (3) to allow health agencies to monitor the occurance and spread of infection of the virus within the state; and

(4) to allow health agencies to contact the infected when specific anti-viral treatment becomes available were discussed to discover whether the requirement of reporting names logically achieved the concededly important state interest of reducing incidence of infection and disease. Under the author's analysis, the state failed to justify keeping a list of names. The interest in counselling could be accomplished better by tying it to the testing. That is, if counselling is part of the testing, once a person is tested and counselled, the state had no further interest in counselling. The interest in monitoring the spread and occurence of the infection, is a matter of statistics, therefore names add nothing. Furthermore, the transience of a population and the reluctance of individuals to be tested in Colorado make this particular goal difficult to achieve with any degree of accuracy. Last, it is suggested that those people who know they are infected with HIV have a strong personal interest in knowing the latest medical and scientific discoveries about HIV and AIDS. Most likely they would know of the existence of a cure before the health authorities. A list of names will not assist health authorities to inform the unregistered or, considering the mortality rate of AIDS, those persons already dead when a cure is discovered. In short the law did not further any aspect of Colorado health

authorities' AIDS related activities which could be accomplished without requiring the identification of the group members. 55

The analysis of the Colorado law shows that by combining an analysis of the group's characteristics and the means employed by the state, under heightened scrutiny the requirement of names does not establish a state's substantial interest when the goal is the reducing of HIV infection. It is important not to confuse the state's interest in public health which is always important (and in the case of dangerous disease could be called substantial or even compelling without eliciting much objection) with the means by which the state would achieve its goal. Those means discriminate against a group of people; the law officially creates a classification. Where that group is persons with positive HIV antibody status, heightened scrutiny should be the standard of review to determine a denial of equal protection.

Substantive Due Process and the Right of Privacy

As discussed earlier, the right of privacy has developed in piecemeal fashion. It existed in bits and pieces scattered over a wide area of the law including property law (trespass) and tort law (defamation, unauthorized use of photographic portrait in advertising was an invasion of privacy). Although not recognized as a constitutional right of privacy in the 1920's, the Supreme Court overruled state court decisions that interferred with the liberty rights of parents to control the upbringing and education of their children. ⁵⁶

In <u>Griswold v. Connecticut</u> 57 in 1965, the Supreme Court recognized the constitutional right of privacy. A Connecticut statute which forbade the use of and aiding and abetting the use of contraception by married persons was found to be unconstitutional.

Although the justices did not agree on the precise source of the right, the majority determined that there are guarantees emanating from the penumbra of the Bill of Rights and the Amendments to the Constitution. The First, Third, Fourth, Fifth and Ninth Amendments create zones of privacy and the right of marital privacy lies within one of these zones.

The Supreme Court in subsequent cases expanded the right of privacy. It was implied in the Fourteenth Amendment and included personal rights that were fundamental. The state needed a compelling interest to interfere with individual conduct relating to marriage, procreation, so and contraception. The focus of these cases was on personal decision making in the zones of privacy, and that aspect of the right of privacy generally is called the right of autonomy. The right has been characterized as concerning intimate, personal matters or family matters, but Bowers v. Hardwick a upholding a Georgia prohibition on private, consensual, homosexual sodomy, evidences that not all intimate, private matters are protected.

Whereas the autonomy privacy right is limited to certain subjects, there is a broader right of privacy which seeks to limit disclosure of personal information. This right has been given several names: the right of confidentiality, the interest in avoiding disclosure

of personal matters and right of informational privacy. For the sake of simplicity, it will be referred to as the right of informational privacy.

This right has its roots in the tort law of defamation which protected the individual's reputation against defamation by slander (oral) and libel (written) falsities. 62 The main defense against defamation is the truth of the words spoken or written so the disclosure of highly objectionable but true facts was not actionable. But it is not unreasonable for an individual to desire to limit the information that others have about him or her, because even the truth can be quite damaging. The tort of invasion of privacy is of some assistance, but it is limited to the disclosure of highly offensive and objectionable facts. 63

The issue of whether the individual had a liberty interest in his reputation came before the Supreme Court in Paul v. Davis. 64 The plaintiff had been arrested for shoplifting but the charge was dismissed. Nonetheless, his name and picture were included in a flyer depicting active shoplifters that was circulated by the police to local merchants. The plaintiff asserted that the resulting damage to this reputation was a deprivation of a liberty interest without due process of law. The Supreme Court disagreed and found that reputation alone was neither a liberty nor property interest. In distinguishing some prior rulings, the court indicated that an interest more tangible than reputation was needed. Furthermore, the Supreme Court found that the circulated flyer did not affect the right of autonomy. 66 In effect, a general right to control

information about oneself was not recognized in Paul v. Davis.

The next year, the Supreme Court seemed to acknowledge that there was an interest in avoiding the disclosure of highly personal information, but this interest was not a fundamental right. The case was Whalen v. Roe 67 which involved a New York law that required a copy of a physician's prescription for the New York equivalent of the federal Schedule II dangerous drugs 68 be submitted to the State Health Department. The prescription form contained information about the identification of the patient, prescribing physician, dispensing pharmacist, the drug, the dosage and the patient's age and address. The forms were retained for five years and then destroyed. Public disclosure of the patients' names was prohibited and access to the information was restricted to a small number of health department employees.

The plaintiffs who were physicians contended that the statute violated two areas of privacy. The first was their interest in avoiding disclosure of personal matters. The second was their right of autonomy -- their independence in making important decisions about their health. They were concerned that disclosure of their identities would cause them to be labeled drug users and would damage their reputations.

Therefore they would be reluctant to use and the physicians reluctant to prescribe the drugs thereby affecting their decision to seek treatment.

The Supreme Court disagreed. The safeguards were adequate to prevent unwarranted disclosure and, in fact, the record did not

support that disclosure had occurred. Any court ordered disclosure (which could arise if a patient or physician was accused of violating the statute) could be judicially supervised to prevent damage to reputation. The disclosure of the prescription form to the health department was similar to the disclosures required by the modern practice of medicine. The requirement for the information was not automatically an invasion of privacy.

The opinion stated that "[t]he right to collect and use such data for public purposes is typically accompanied by a concomitant statutory or regulatory duty to avoid unwarranted disclosures." 71 The importance of the safeguards is clear, because the Supreme Court would not give an opinion on questions involving a system that lacked precautions against unwarranted disclosure.

What the Supreme Court did was to balance the state's interest in protecting the public health and in preventing drug abuse against the patients' right of informational privacy. This balancing test indicates that informational privacy is an important right requiring heightened scrutiny. If it were not, then the Supreme Court would have used a minimal scrutiny test, 72 and its discussion of the safeguards against disclosure would have been unnecessary.

The Supreme Court's treatment of the right of informational privacy as an important but not fundamental right is affirmed in Nixon v. Administrator of General Services. 73 In that case, the former president made several constitutional challenges against the Presidential Recordings and Materials Preservation Act, including an

assertion that the act violated his right of privacy. The Act required all of the presidential papers and recordings be submitted to archivists for screening. Purely personal, private materials would be returned to Nixon. The Supreme Court decided that the district court properly balanced the public's interest in preserving the materials on official duties against the invasion of privacy that a screening would cause, and it found that screening the materials was a reasonable response to the mingling of a small amount of personal material with a vastly larger amount of nonprivate material. 75

The Supreme Court agreed that the Act was not an unconstitutional violation of Mr. Nixon's right of privacy. It cited Whalen for the proposition that the individual's interest in avoiding disclosure of personal matters was one element of privacy. The Nixon did not give up all expectation of privacy when he became President, but the Supreme Court found that this expectation applied to very little of the presidential materials. The informational privacy must be balanced against the state's interest. The opinion states that

the merit of the appellate's claim of invasion of his privacy cannot be considered in the abstract; rather, the claim must be considered in light of the specific provisions of the Act, and any intrusion must be weighed against the public interest in subjecting Presidential materials of appellant's administration to archival screening.

Although there are some differences between the Whalen and Nixon cases -- in Whalen personal information was to be submitted to the state for retention whereas in Nixon personal materials would be screened out and returned -- both cases recognized the individual's right of informational privacy as an important interest requiring heightened scrutiny for review. The weakness of the cases is that they give little foundation for this new right. This has allowed the federal circuit courts to apply either Paul v. Davis reasoning or Whalen v. Roe to plaintiffs' assertions that their right of informational privacy has been impaired.

The Courts of Appeals

Four cases from the 1980's are of particular interest for assessing the treatment of informational privacy. Three of the cases involve the recognition by three circuits of medical information as part of informational privacy. A fourth case shows the limits of the right.

Both General Motors Corporation v. Director N.I.O.S.H. 78 and U.S. v. Westinghouse 79 concern investigations by the National Institute of Safety and Health into occupational disease. The corporate employer became the "champion" of its workers' right of privacy in an effort to refuse access to medical records. In General Motors v. Director N.I.O.S.H., the Director issued a subpoena for medical records in connection with research into skin diseases of employees who worked in the "wet rubber process." The records in question were those of 490 employees (out of 704) who did not execute consent to release

the records. General Motors was concerned about releasing information which employees had given to the plant physician in confidence.

N.I.O.S.H. wanted names so that contact could be made with the employees to confirm or refute suspected cases of occupational skin disease. The Sixth Circuit cited Whalen for balancing the individuals' privacy interests against the public agency's statutory right of access. The court concluded that "with proper security administration, the Institute should be able to complete comprehensive health hazard evaluation ... without jeopardizing the constitutional rights of the individuals involved." (The case was remanded to the district court to formulate and implement security measures).

In <u>Westinghouse</u> N.I.O.S.H. was investigating allergic reactions to and the effect on the respiratory system of a chemical called HHPA (hexahydrophthalic anhydride). Westinghouse wanted the employees first to consent to the release of their medical records and the government to provide written assurance that the contents of the records would not be released to third parties. N.I.O.S.H. would agree only to removing the employees' names and addresses before publishing the data. The Third Circuit found that medical records were well within the type of materials entitled to informational privacy protection and voted that far more personal information was requested by the government than had been requested in <u>Whalen</u>. 81 The court listed seven items to be considered in balancing the government's interest in occupational safety and health and the right of privacy: 1) the type

of record, 2) the information contained in it, 3) the potential for harm in subsequent nonconsensual disclosure, 4) the injury from disclosure to the relationship in which the record was generated, 5) the adequacy of safeguards to prevent unauthorized disclosure, 6) the degree of need for access, and 7) the existence of statutory, articulated public policy or other recognizatble public interest in access to the information. 82 Taking these factors into account the government's substantial interest in occupational safety and health and the public's interest in N.I.O.S.H. investigations justified the minimal intrusion into the medical records. 83

Farnsworth v. Procter and Gamble Co. 84 was a products liability suit involving the toxic shock syndrome. The plaintiff intended to introduce into evidence a C.D.C. study on toxic shock syndrome.

Defendant wanted the names and addresses of the women who participated in the study in hope that it could discredit the study. The information given to the C.D.C. was highly personal and included medical histories and sexual practices. The C.D.C. feared that disclosure of the participants' identities and the potentially embarrassing information would inhibit future studies (C.D.C. asked the women for consent to release the information and 32 agreed). The Eleventh Circuit found that the C.D.C.'s interest in keeping the participants' names confidential outweighed the discovery interests of Proctor and Gamble.

85 The court noted with approval what amounts to a public policy interest: the need to encourage voluntary reporting to C.D.C. by participants in its studies.

86 This agreement — the need for voluntary reporting —

was not discussed in either <u>General Motors</u> or <u>Westinghouse</u>. There may have been an assumption that the workers felt free to talk to the plant physician or that any disclosure would not affect this communication (however, <u>General Motors</u>, the Sixth Circuit noted that there is no federal physician-patient testimonial privilege).

Although the federal courts seem to accept the interest in information privacy of medical records, they have not extended it to all types of personal information. The Sixth Circuit in J.P. v. DeSanti 88 chose to apply the reasoning of Paul v. Davis instead of Whalen. The case concerned the post-adjudication use of compiled social histories of juveniles in Cuyahoga County, Ohio. The court held that although the Constitution protects several specific aspects of privacy, particularly those extremely intimate matters related to the autonomy right, there is no general right to nondisclosure of private information. 89 The social histories were "indistinguishable" from the shoplifter flyer in Paul v. Davis.

Furthermore, the court ruled that neither Whalen nor Nixon overruled Paul v. Davis.

From this discussion of the Fourteenth Amendment's protection of privacy, there is no absolute right to nondisclosure of private personal information. For the HIV carrier, this means the protection is inadequate. There are some constitutional weapons that can be used to challenge a state law requiring disclosure of the identities of individuals who are HIV antibody seropositive. The most successful attack involves a combined assertion of denials of equal protection and substantive

due process. The HIV carriers are a sensitive classification thereby requiring heightened scrutiny of the state's interest — its means of achieving the goal, which in the HIV context will be public health. Then the individual's interest in informational privacy is balanced against the state's interest, using the seven factors of Westinghouse. An eighth factor from Farnsworth, the public policy in favor of nondisclosure, must be part of the balancing. These factors are not equal in weight. In order to complete the federal constitutional picture, the judicial attitude toward public health and the arguments on public policy must be examined.

Public Health

Preservation and protection of the public health is a state interest with a long history of judicial deference. The Supreme Court recognized public health as a legitimate subject of the state's police power in 1905 in Jacobson v. Massachusetts. 91 The case involved mandatory vaccination. The court deferred to the legislature's determination that vaccination was the best method for preventing small pox. It required only that the state's actions be reasonable. By 1922 the Supreme Court recognized preventive medicine in another vaccination case, Zucht v. King. 92 The Supreme Court determined that schools could require vaccination as a prerequisite for attendance. There was no requirement that there by an actual outbreak of small pox to justify the state's action.

One should not infer that a court unquestioningly accepted the state's expressed intent. The quarantine case of <u>Jew Ho v. Williamson</u> 93 in 1900 shows the Ninth Circuit accepting the medical evidence that

there were deaths from Bubonic plague in San Francisco and that quarantine was an appropriate means of protection. However, the court reviewed how the quarantine was enforced and found that the quarantine was used to discriminate against Chinese people in violation of the equal protection clause of the Fourteenth Amendment. There was no medical basis for the manner in which the quarantine was applied (skipping houses occupied by non-Oriental people but quarantining only the Chinese in the same area).

A good faith, although possibly mistaken, disclosure by a physician to a hotel owner of a contagious, dangerous disease -- syphilis -- was allowed in the 1920 case of Simonsen v. Swenson.

This is another example of judicial deference to the interest in protecting the public health.

These cases show a judicial restraint from intervening in state actions. If there was a rational relation between the means and the goals, the individual could lose his liberty (quarantine), be subjected to unwanted medical treatment (vaccination) or suffer damage to his reputation (disclosure of a loathsome disease). The deference to public health was established long before major advances in medicine and before the Supreme Court cases on privacy. One author suggests that although the medical approach to disease has changed, the human approach -- fear -- has not.

95 There is a conflict between medical and lay perceptions of a health problem, a conflict which places pressure on public health authorities to act for inappropriate responses.

Courts must evaluate the medical evidence in order to determine the legality of the state's action. It has been suggested that the analysis involves the two parts of a public health decision: risk assessment and response. 97 Risk assessment is a medical determination of the severity of the disease and its manner of transmission. A disease could be mild yet highly contagious like chicken pox (in children; in adults chicken pox is not mild), or fatal but not contagious like cancer. Medical knowledge decides the threat of a disease to the public. The response or state action must be medically sound. In forming a response to a public health problem, the state should not choose one that is restrictive of individual rights if a less restrictive, comparable response is available. 98 Public health protection is a legitimate state interest but calming the irrational undifferentiated fears of the community is not a compelling, important or legitimate state interest.

The cases of New York Association for Retarded Children v. Carey and La Rocca v. Dalsheim 101 are illustrative of a more active approach by the courts to the public health problems of hepatitis B (which is transmitted much like HIV) and AIDS. In Carey, the New York City Board of Education attempted to exclude a group of retarded children who were hepatitis B carriers from regular school classes. The action was prompted by the considerable concern by parents and teachers over a case of possible hepatitis in a public school (the disease was hepatitis A, a different disease). The Board was aware that a group of retarded children from a state home were hepatitis B carriers,

but it did not attempt to identify all the carriers, normal and retarded children, in the school system. 102 At trial the Board was unable to demonstrate that the presence of the hepatitis B carriers in the classroom created a health hazard. 103 In fact, there was considerable evidence on behalf of the children that isolating them was detrimental to their development and would stigmatize them. 104 The Second Circuit looked carefully at the Board's risk assessment and found it faulty. Because the medical evidence did not support the Board's response to the perceived health problem, the response was invalid.

La Rocca involved inmate fear of AIDS in New York's Downstate

Correctional Facility. The majority of the prisoners came from New

York City, which had the largest number of persons with AIDS in the

United States. The court noted that the majority of persons with

AIDS were either homosexual or intravenous drug users and that homosexual

activity (consensual and forcible) and drug use occurred in the prison.

In effect, Downstate was a "potentially high risk setting for AIDS."

At the time of trial, HIV had not been discovered, and the court

acknowledged the lack of medical knowledge on how AIDS was spread and
the relationship between contact and infection. Plaintiff prisoners

desired that all inmate movement into and out of the prison be halted

until all inmates and employees were examined for AIDS; then they
requested removal of all persons with AIDS from the prison to a hospital.

The court considered medical evidence of the communicability of the disease

and the precautions employed within the prison. A considerable portion of the opinion discusses the infection control measures used by persons who care for or clean up after those prisoners diagnosed with AIDS (the same measures as were used for hepatitis B). The court did not allow itself to be influenced by the medical unknowns that surround AIDS and fuel the prisoners' fears. Instead it directed that public health literature be distributed to each inmate at the prison. 106

Relying on the medical evidence, the court denied the request for an AIDS examination because none existed, and it denied the request for removal of prisoners with AIDS because it was not medically necessary. Based on the best medical information available on AIDS, the court concluded that infection control measures were appropriate for controlling contact between prisoners with AIDS and the rest of the prison population. The court insinuated that the prison authorities had a duty to prevent forcible homosexual acts because those acts already were prohibited and the state had a duty to provide a safe and humane place of confinement. 109

Carey and La Rocca are similar in that they concern a demand for a public health response to two dangerous, contageous diseases that share transmission characteristics, a demand which was not based on sound medical evidence and mhich was motivated by fear. The courts carefully examined the medical evidence and made their own risk assessment.

Although there was concern for the individual rights of the people involved, the courts would defer to the state's public health argument if it was medically sound. In the context of public health

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and HIV testing, Carey and La Rocca indicate that the state's means of protecting the public health will be given tremendous weight if they are supported by medical evidence and notirrational fears. Mandatory testing and disclosure to health authorities of the identities of the seropositive individuals could be justified if the HIV were proved transmittable through casual contact. In a case involving medical necessity, the individual's rights will be overridden. This argument is applicable to mandatory premarital HIV testing: there is no medical necessity. The analogy to premarital syphilis testing is useful. Only 21 states still require it. Other states repealed their testing laws after studies showed that few cases of syphilis were detected through the tests. 110 Premarital testing for HIV antibodies will detect few because young heterosexuals are not a high risk group. It will overburden the laboratories that perform the tests which may increase the risk of false positive tests. Furthermore, the connection between premarital testing and stopping the spread of infection is tenuous. A marriage license is not a prerequisite for sexual intercourse. It is a matter of speculation how many couples have been sexually active prior to marriage. If one partner were infected with HIV, it is likely the other would be also by the time they applied for the license. Fortunately the incidence of HIV infection is low so the actual number of seropositive individuals that mandatory testing would detect is small. Also in view of Loving v. Virginia, 111 it is doubtful that the positive test result would constitute a compelling state interest that would justify the impairment of the right to marry.

At the present time, AIDS as defined by the C.D.D. is a reportable disease in all states. Positive HIV antibody test results are reportable in Colorado, Montana, Arizona, Idaho, South Carolina and Wisconsin. Only Colorado requires that identities be reported. As discussed earlier the requirement for names does not assist Colorado health authorities in their AIDS related activities. The purposes of the statute can be achieved without names. Since there is no treatment or cure for or vaccine against AIDS or HIV infection and the progression from asymptomatic HIV infection to ARC or AIDS is unpredictable, the medical basis for the Colorado reporting requirement is weak. Therefore, when the public health interest is one of the factors either in the balancing test between the individual's interest in informational privacy and the state's interest or in the court's review of the state's interest in discrimination against a sensitive classification of people, the court will presume it to be valid unless it is medically unjustified. Public Policy

The public policy against disclosure of private, personal information is another factor to be considered in the heightened scrutiny balancing test. Public policy reflects the reality that most individuals will not reveal things about themselves that will later cause them harm. It can also be used to encourage individuals to undergo procedures that may benefit the state or the public that otherwise would be too burdensome.

As an analogy, the policy of disclosure of the natural parents' identity in adoption is useful in forming a policy of nondisclosure in HIV antibody testing. The natural parent may be an unwed mother, and revelation of this fact at a later date could damage her reputation, subject her to ridicule, or harm her future relationships. 113 It can be argued that fear of the consequences of disclosure would cause the mother to terminate the pregnancy. Nondisclosure of adoption records also frees the child from the stigma of illegitimacy. 114 A state that desires to encourage adoption will guarantee some type of nondisclosure. Protection of the identity of the natural parent is strictly a policy matter; it is not a right. There are several states that have open adoption records, records that remain sealed until the adoptee reaches his or her majority, or records that can be opened for good cause. 115

A similar public policy applies to HIV antibody testing: the state can encourage testing by guaranteeing confidentiality. The U.S. Public Health Service practice is to maintain confidentiality of the health records of infected persons. It acknowledges that when reporting of infected individuals and tracing of their sexual contacts is required, those who fear they are infected avoid testing and medical treatment, i.e., "go underground." 116 Blood services also encourage nondisclosure of blood donor identities and information given by the donors. Blood donor personal health histories are important for determining the suitability of blood for transfusion. Because false negatives occur in serological testing, the honesty

and accuracy of the health history may indicate a reason for screening out that donor's blood. 117 Nondisclosure promotes the safety of the blood supply. It may also encourage a person with uninfected blood to be a donor: many people would be deterred from donating if they thought that the information on the health history might affect their employment, reputation or personal relationships if it were disclosed. 118

STATES - SECOND TRANSPORT BESERVED.

The public policy argument in Farnsworth, 119 that the participation in national studies requiring intimate information should be encouraged, is valid in AIDS research and HIV antibody testing. A tremendous need exists for research on AIDS. This research requires subjects to discuss very personal matters that may involve sexual practices illegal in many states and illegal drug use. The fear of prosecution or of stigmatization as a homosexual or drug addict can deter needed participation and hamper research unless nondisclosure is guaranteed. That same stigmatization and potential for discrimination in employment, housing and insurance might discourage the ordinary person, high or low risk, from being tested. To allay these fears, many testing facilities do anonymous testing and the identities are never known.

IV . STATE LAW PROTECTION OF PRIVACY

State laws protect the individual's privacy in several ways that affect HIV testing. A right of privacy may exist in the state's

constitution or be recognized by statute. A physician-patient testimonial privilege may exist, and there may be a statutory requirement of nondisclosure of medical records. Althouth the impact of AIDS and HIV antibody testing is relatively recent, a few states have passed legislation that specifically guarantees privacy for those with AIDS or HIV infection.

State Constitutional Right of Privacy

Alaska, California, Florida and Montana state constitutions guarantee a right of privacy. 120 The extent of that right is a bit uncertain and the right is not absolute. In Falcon v. Alaska Public Offices Commission, 121 a physician-legislator challenged a statute requiring him to divulge sources of income as violating the right of privacy of his patients. The Supreme Court of Alaska indicated that the standard for justifying the invasion of privacy depended on the type of privacy. 122 The disclosure law did not violate privacy when all it showed was that a person received medical treatment. However, when there was something peculiar or characteristic about the physician that revealed by implication the type of treatment rendered, i.e. if the physician was a well-known cancer specialist or sexual dysfunction therapist, disclosure of the physician's sources of income, his patients' names, violated their privacy. The court felt the statute could be amended to protect privacy by exempting certain groups.

South Florida Blood Services v. Rasmussen 123 is important because it involved AIDS, the right of privacy of blood donors in Florida and

public policy that favored voluntary blood donation. Plaintiff's decedent was injured in an automobile collision and received blood transfusions while in the hospital. He later developed AIDS and died. The transfused blood was the suspected source of the AIDS. In order to prove aggravated damages against the owner/driver of the automobile, plaintiff sought the names and addresses of the donors whose blood he received. South Florida Blood Service provided the hospital with the blood and appealed the trial court's order to produce the names. The case went to the District Court of Appeals which overturned the trial court's order 124 and then to the Florida Supreme Court which affirmed the District Court of Appeals decision. The Supreme Court cited the District Court's opinion wherein it noted that "AIDS is the modern day equivalent of leprosy. AIDS or a suspicion of AIDS, can lead to discrimination in employment, education, housing and even medical treatment." 125 The Supreme Court stated that the public's response to AIDS made the protection of the donor's privacy a critical matter and therefore disclosure implicated "constitutionally protected privacy interests." 126 South Florida Blood Services established that the right of privacy extended to medical information where disclosure would have devastating consequences. It also allowed a third party to assert another's right of privacy. This is particularly important in the area of HIV testing where a testing facility or a blood bank has the identifying information but might not be able to assert the physicianpatient privilege, as in Florida, where there is none. The judicial

recognition of the disastrous effects on reputation and livelihood that public knowledge of HIV infection has, militates toward a policy argument against disclosure. South Florida Blood Services is a recent case and it is difficult to predict how far it will be applied. It could be limited to its facts and then would not protect blood donor records if the blood service was accused of negligence, or it might not apply to disclosure of donor records to a state health agency when there were safeguards against subsequent unauthorized disclosure.

The discouraging aspect of both Falcon and South Florida Blood Service is the level of importance the courts placed on the state constitutional right of privacy. The Alaska Supreme Court distinguished the federal right of privacy (autonomy) and the need for a compelling state interest from the right of privacy in the Alaska constitution to justify invasion of that right with the varying levels of gratification required for the Alaska state right. 128 The court may have been following Whalen although the case was not cited. The varying levels of justification in Alaska could correspond to the fundamental right of autonomy, privacy and the lesser important interest in informational privacy. In South Florida Blood Services, the District Appellate Court treated the state constitutional right of privacy as an important interest and used the heightened scrutiny balancing test. 129 The Florida Supreme Court cited Whalen and also interpreted the right of privacy to be that of an interest in informational privacy. 130 For the HIV infected person seeking to protect his or her right of privacy under a state constitution, if the privacy can be characterized as informational privacy rather than autonomy privacy, the level of scrutiny will be the same as under the federal constitutional right of privacy: heightened scrutiny. Therefore, the state right does not give greater protection than the federal right in preventing disclosure.

Physician-Patient Privilege

To a limited extent, the HIV seropositive individual may find protection against unwarranted disclosures in the physician-patient privilege which prevents forced disclosure in judicial proceedings of confidential information. The limitations are many because the privilege is testimonial and applies only in court proceedings and related matters. It does not exist in all states. For example, Florida does not have the physician-patient privilege, but it has the narrower psychotherapist-patient privilege. 131 The privilege is subject to statutory definition and may be interpreted broadly to cover any information acquired by a physician in the course of treating the patient or narrowly to mean only communication, thereby excluding diagnosis and treatment. 132

Courts have not limited the term "physician"; information gathered by the physician's agents, nurses or assistants is covered by the privilege. Hospitals which hold patient records are allowed to assert the privilege, 133 and in Arizona they are required to assert it. 134 The California Supreme Court extended the meaning of physician to allow a drug manufacturer to assert the physician-patient privilege where confidential information was relayed by the physician to the manufacturer

for the purpose of treating a patient who had an adverse reaction to one of the manufacturer's products. 135 As more experimental drugs are developed to treat AIDS there may be many drug companies which might be called upon to assert the physician-patient privilege in order to protect patients' privacy.

It is clear that the physician-patient privilege will prevent disclosure of HIV antibody status in judicial proceedings unless the patient waives the privilege. It will not protect the patient from disclosure in other contexts such as reports required by law to public health authorities. There is a question whether a blood service could assert the privilege. 136 Blood services are supervised by physicians. The blood donor who is HIV antibody positive usually will be offered counselling by a staff member. Although the donor may be unaware of the physician's role in the blood service, the counselling he or she receives is part of the physician's supervisory responsibility, and can be the basis of an argument favoring the physician-patient privilege for blood services (through their medical directors). Blood services hold great quantities of personal information from both the HIV antibody test results and the personal health histories. The needs for honest and accurate health histories and for encouragement of voluntary blood donation, constitute a strong policy reason for extending the privilege.

Medical Records

The confidentiality of medical records is controlled by atatute.

There is great variation among the statutes. For example, in Virginia

the statute is very broad and exempts all medical records from disclosure, 137 whereas in North Carolina there is no general guarantee of confidentiality but, instead, certain types of medical records are confidential: records held by the Department of Human Resources, 138 clinical records of cancer patients, 139 and records concerning venereal diseases are examples. 140 The importance of a medical record statute to an individual who is HIV antibody positive is that it prohibits unauthorized disclosures outside of judicial proceedings. If the HIV antibody test results are not considered to be medical records, the statute provides no protection. Head v. Colloton 141 illustrates a useful expanded meaning of medical record. In that case a leukemia patient sought the name of a potential bone marrow donor for a life saving bone marrow transplant. The potential donor's name was in a state hospital's bone marrow transplant registry despite her refusal to be a donor for anyone outside b€ her family. The hospital refused to disclose the donor's identity or contact her about the plaintiff. In reviewing the trial court's order that the hospital notify the potential donor of the plaintiff's need, the Iowa Supreme Court found, based on a physician-patient relationship between physician and donor, the donor was a patient and the record of tissue and blood typing was a medical record, thereby exempt from disclosure under the Iowa public records statute. The case was not considered under the statute involving the physicianpatient privilege because that statute was narrowly construed and found to be inapplicable. 143 Head v. Colloton has the potential

of being the basis of a persuasive argument that a blood service's donor deferral registry (the registry of donors whose blood was rejected) or other records containing evidence of HIV antibody status are medical records as an alternate position when the physician-patient privilege cannot be used. In another context, the case could be used to argue that test results at private testing facilities are medical records and therefore are confidential. If a medical records statute has exemptions for state hospital licensing inspectors or other state agencies to review records for many purposes, 144 the statute will not prevent disclosure of HIV antibody status to the state, but would prevent private individuals from obtaining the records.

Specific HIV Antibody Testing Legislation

Other than the uncertain meaning for future health of a positive HIV antibody test, the greatest fear of HIV antibody testing is the unauthorized disclosure of the results or even the fact that the test was performed. In response, few states have enacted legislation to guarantee the confidentiality of the testing. The simplest statute is from Massachusetts ¹⁴⁵ and requires written consent from the subject for the test and for disclosure of the results. It prohibits health care facilities, physicians and health care providers from disclosing the identity of the test subject to anyone without consent. The Maine statute provides that "no person may disclose the results of a test for the presence of an antibody to HTLV-III, a test that measures the HTLV-III antigen" except to the subject of the test, the subject's designated health care provider

or persons authorized by the subject to receive the information. 146 Civil penalties for violation of the statute, in addition to actual damages and court costs, are fines up to \$1,000 for negligent disclosure and up to \$5,000 for willfull disclosure.

The Florida statute takes a very broad approach. Instead of referring to a test for the HIV antibodies or HIV, the statute addresses serologic tests. 147 It does not specify the type of test. One could conclude that it would cover such serologic tests as a T-lymphocyte count, the hepatitis B surface antigen test, or any of the serologic tests used in evaluating the body's immune system. This type of statute should be particularly good for protecting the confidentiality of tests of persons with HIV infection, ARC, or AIDS.

Both California 148 and Wisconsin 149 require written informed consent for the HIV antibody test. They prohibit anyone from being compelled to reveal the identity of any person who has been the subject of an HIV antibody test. Civil and criminal penalties, in addition to actual damages and court costs, are a maximum of \$1,000 for negligent disclosure and a maximum of \$5,000 for intentional disclosure. The criminal penalty for disclosure that results in bodily or psychological harm (and economic harm in California) is imprisonment, not to exceed one year in California, and nine months in Wisconsin, or a fine not to exceed \$10,000.

In addition to the protection of confidentiality of HIV antibody testing, California specifically protects the confidentiality of AIDS research records by prohibiting disclosure by anyone in possession of

the record; by declaring the records to be exempt from discovery and by prohibiting compelled disclosure of the records. 150

Similar protection is afforded under the New York Public Health

Act to protect the investigations and reports of the Acquired Immune Deficiency Syndrome Institute of the department of health. 151

The best features of the statutes are, in addition to the prohibition on unauthorized disclosure, the requirements for informed consent, the criminal sanctions, the civil remedies and the protection of research records. By delineating the circumstances under which disclosure is allowed -- to whom and for what purpose -- and by prescribing punishments for violations, the statutes provide the widest protection of the right of privacy. From the viewpoint of the person infected with HIV, the statutes could be improved. The Massachusetts law is vague on sanctions for unauthorized disclosure and makes reference to another statute on fraudulant practices. The criminal sanctions in California and Wisconsin are not severe. The laws allow disclosure to the public health services. If those public health services are required to maintain the confidentiality of the information then privacy is still protected. From a practical perspective, the larger the number of individuals who have access to the information or the greater the number of authorized disclosures, the risk of breaches of privacy increases. The most useful statute is one that strictly limits the persons authorized to receive the information; that has the widest possible number of tests covered as confidential, as is accomplished in Florida by designating serologic tests instead

of HIV antibody tests; and that also limits the circumstances under which the results may be disclosed. Allowances should be made for research and epidemological studies, but release of names or other

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of HIV antibody tests; and that also limits the which the results may be disclosed. Allowances research and epidemological studies, but release types of identifying data must be prohibited.

V.CONCLUSION

AIDS is a fatal disease that has afflicte 36,000 people in the United States. It is caus Immunodeficiency Virus, HIV, which has infected 1,800,000 to 3,600,000 asymptomatic persons. If many of these will develope the disease but the percent. The majority of the AIDS patients are bisexual men followed by intravenous drug users is regarded as acceptable by the general public of fear of the disease and loathing of its suff has resulted in discriminatory action against the and persons infected with the HIV. The HIV and was originally developed to screen the nation's used to determine a person's antibody status. sources for the testing, many of which such as highly personal information about the test subfacilities have names and addresses; other test The potential for unauthorized disclosure information including antibody status is of greaters. AIDS is a fatal disease that has afflicted approximately 36,000 people in the United States. It is caused by the Human Immunodeficiency Virus, HIV, which has infected an additional 1,800,000 to 3,600,000 asymptomatic persons. It is uncertain how many of these will develop the disease but the estimate is twenty percent. The majority of the AIDS patients are homosexual and bisexual men followed by intravenous drug users, neither group is regarded as acceptable by the general public. The combination of fear of the disease and loathing of its sufferers by the public has resulted in discriminatory action against both persons with AIDS and persons infected with the HIV. The HIV antibody blood test which was originally developed to screen the nation's blood supply is being used to determine a person's antibody status. There are several sources for the testing, many of which, such as blood banks, also have highly personal information about the test subject. Some testing facilities have names and addresses; other test anonymously.

The potential for unauthorized disclosure of personal, private information including antibody status is of great concern because of the devastating effect it may have on the test subjects' insurability, employment and personal relationships. Most of the federal laws designed to protect privacy are of little use because they are applicable to very limited circumstances, such as drug treatment programs, or prevent disclosure to the public while allowing full disclosure within the government. A similar situation exists under the U.S. Constitution. Specific types of privacy are protected, but there is no right of privacy that is a fundamental right. The best approach against a law that calls for the disclosure of identities and other personal information of persons who have positive HIV antibody tests is a combined equal protection and substantive due process argument. The HIV infected people are a discrete and insular minority who are stigmatized and discriminated against. Therefore positive HIV antibody status is a sensitive classification requiring the heightened scrutiny level of review of any law that requires disclosure of the identities of the class members. Also the required disclosures are violations of the person's right to or important interest in informational privacy which also requires heightened scrutiny.

Heightened scrutiny is a balancing test. Among the elements that are considered are the manner in which the state proposes to further its responsibility for public health and the public policy against disclosure. Clearly case law shows a strong judicial deference to public health. Courts must be urged to examine the basis of public health decisions and require the state's method of achieving its goals to be medically sound and the least instrusive as possible. A public

policy of nondisclosure would encourage HIV infected people to be tested and actually further the state's interests.

A few states have a constitutional right of privacy but state judicial treatment of privacy of personal information is much like the federal interpretations. It is an interest in informational privacy and the heightened scrutiny balancing test is applied with results comparable to the federal cases. Other state laws that might protect the HIV antibody seropositive individuals privacy are the physician-patient privilege (applicable to court proceedings and related matters) and the medical records statute (applicable to nonjudicial disclosures). Unfortunately these laws vary greatly from state to state and do not exist in many states.

The best protection of informational privacy or confidentiality as it is also called, is the state law that directly addresses HIV antibody or antigen tests or serologic tests. It should limit disclosure to the subject and his or her designated physician or health care provider and prohibit other disclosures with the exception of statistical data to public health agencies for epidemiological studies. To be effective, the statute must contain civil and criminal penalties for violations and these must be enforced. At present there are only five states with this type of law. It is hoped that more state legislatures will decide that the best way to stop the spread of HIV infection is to encourage voluntary testing which can be accomplished only if the test subjects' right of privacy is protected.

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- 6. American Red Cross, AIDS: The Facts (1986).
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- 27. 42 U.S.C. § 242m(d) (Supp. 1983).
- 28. Katz v. United States, 389 U.S. 347, 350 (1967).
- 29. NAACP v. Alabama ex rel. Patterson, 357 U.S. 449 (1958).
- 30. Id.
- 31. Id. at 463.
- 32. Shelton v. Tucker, 364 U.S. 479 (1960).
- 33. Id. at 155.
- The Interest in Limited Disclosure of Personal Information: A Constitutional Analysis, supra, n. 21 at 153.
- 35. Id. at 155.
- 36. 389 U.S. 347 (1967).
- 37. Id. at 351.
- 38. Id. at 352.
- 39. 433 U.S. 425 (1977).
- 40. The Interest in Limited Disclosure of Personal Information: A Constitutional Analysis, supra, n. 21 at 159.
- 41. There is a U.S. Army court-martial case involving a soldier who is

HIV antibody positive and is accused of engaging in unprotected sexual intercourse in violation of lawful orders. It does not appear that the right against self-incrimination is at issue in the case. See Goodman, The AIDS Carrier as Criminal, Wash. Post, June 9, 1987, at A21.

42. <u>Dandridge v. Williams</u>, 397 U.S. 471, 485 (1970).

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- 43. Loving v. Virginia, 388 U.S. 1 (1967).
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- 48. City of Cleburne v. Cleburne Living Center, 105 S. Ct. 3249, 3259 (1985).
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- 63. <u>Id</u>. § 117.
- 64. 424 U.S. 693 (1976).
- 65. See, Wisconsin v. Constantineau, 400 U.S. 433 (1971).
- 66. 424 U.S. 693, 713
- 67. 429 U.S. 589 (1977).
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- 69. 429 U.S. 589, 599-600.
- 70. Id. at 602.
- 71. Id. at 605.
- 72. Equal protection standards of review were incorporated in the fourth amendment due process by Roe v. Wade, 410 U.S. 113 (1973).
- 73. 433 U.S. 425 (1977).
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- 75. Id. at 456.
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- 77A. 424 U.S. 693 (1976).
- 78. 636 F.2d 163 (6th Cir. 1980), cert. denied, 454 U.S. 877 (1981).
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- 81. 638 F.2d 570,577 (3d Cir. 1980).
- 82. Id. at 578.
- 83. Id. at 579-580.
- 84. 758 F.2d 1545 (11th Cir. 1985).
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- 91. 197 U.S. 11 (1905).
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- 113. Note, Sealed Adoption Records and the Constitutional Right of Privacy of the Natural Parent, 34 Rutgers L. Rev. 451 (1982).
- 114. Comment, Severed Roots: The Sealed Adoption Record Controversy, 6 N.III. U.L. Rev. 103, 105 (1986).
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- 136. Lipton, supra, n. 9 at 167.
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- 138. N.C. Gen. Stat. § 130A-12 (1986).
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